

Aging in Place

What Older Adults and Their Families Want



A Report by The Bazelon Center
for Mental Health Law
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If you, or an older person you care for, has dementia such as Alzheimer's disease, there is important information you should know about the legal rights that are guaranteed to everyone under the Americans with Disabilities Act. We explain in this guidebook—in plain language—what these rights are and how using them can help people who have dementia stay living at home and avoid moving into a facility such as a nursing home.

The Bazelon Center is a national nonprofit organization founded in 1972 by lawyers and mental health professionals. Today it is a leading legal advocate for people with mental disabilities, with the mission of protecting and advancing rights of adults, older adults and children with mental disabilities to exercise meaningful life choices and to enjoy the social, recreational, educational, economic, political and cultural benefits of community living. Using a coordinated approach of litigation, policy analysis, coalition-building public information and technical support for local advocates, we work to end their segregation, incarceration and marginalization and the disintegration of their family structure, and to assure them access to needed services and support.

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Judge David L. Bazelon Center for Mental Health Law, Washington DC

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Aging in Place: What Older Adults and Their Families Want

As we get older, many of us develop medical conditions that make it difficult to keep up with the common activities of daily living such as dressing, preparing meals, going to the bathroom, taking showers or baths, shopping, housekeeping, managing medications, and so on. In the past, older adults with difficulties like these often went into a nursing home. Of course, most people - no matter what age - do not want to live in an institution. Recently there has been a growing effort to help older adults “age in place” by getting them the help they need to live out the rest of their lives at home. For example, in some states, instead of living in a nursing home with your care paid by Medicaid, you can get the same services in your home, such as nursing care, help in dressing or bathing, or help with cooking or housekeeping. Mostly, these programs letting people “age in place” only focus on older people who are frail or have physical issues.

What is Dementia?

According to the Alzheimer’s Association, “Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.”

Just as physical illnesses can put you at risk of having to move from your home, you also can face other issues when you have dementia (such as Alzheimer’s disease). Even if you are not physically ill, dementia can make it hard for day-to-day living at home without help. If you get help from a spouse or partner, a child, or another family member or friend, it can make a huge difference. However, supporting a person with dementia puts a lot of stress on the caregivers too.

Most of us want to be able to choose where we live, and we usually choose to live in our own homes. If you can get the help you need - including supports so family members and other helpers can continue to be caregivers - staying at home can be a good option. If these services are not available, you may have no choice but nursing home care.

In this guidebook, we describe the services that some older people with dementia are able to get, allowing them to age in place. Too many older adults with dementia, their families, and their healthcare providers do not know about programs that are alternatives to nursing home care. Even fewer know older adults with dementia may have a legal right to receive services to help you stay in your home and avoid moving into an institution.

If you have dementia, you may have a legal right to services to help you stay in your home and avoid moving to an institution.

The Americans with Disabilities Act, known as the “ADA,” is a federal law that can help you get the services you need to stay in your own home. It has brought important changes in services to other groups with disabilities, making available services that

let people stay in their own homes. Unfortunately, the ADA has not yet fully helped older adults—particularly those who have dementia. In fact, although opportunities to “age in place” are very much in line with what the ADA requires, very little information about legal rights has been available to older people with dementia and their families.

The purpose of this guidebook is to change that. We will explain:

- What your rights are under the ADA;
- How the ADA is dramatically changing services and allowing other people to live in their own communities;
- How the ADA should be used to help older people with dementia; and
- What you can do to make aging in place a wider reality.

First some basics...

What is the ADA?

For a very long time, people who have disabilities were not able to live in their communities in the same way as people who do not have disabilities. People who use wheelchairs could not get into buildings that had steps, cross a street that had high curbs, or use public restrooms designed for people who could walk. People who were blind could not use an elevator because they could not read the labels on the buttons. Many people with disabilities faced big challenges in shopping or getting to the doctor because it was hard to use buses or other public transportation. As a result, many people with disabilities lived on the sidelines of their communities, sometimes in institutions.

For older adults in particular, many were put into nursing homes or other facilities. On a daily basis, they only saw other people with disabilities and the facility staff. They lived apart from their families, neighbors, friends, and other people we usually come into daily contact with, but don't think much about: the mailman, the checkout person at the supermarket, the bus driver, and so on. As residents of a facility, other people often thought of them—and sometimes they even thought of themselves—as patients, rather than ordinary people.

People with disabilities had to lead second-class lives. They began speaking out prompting the United States Congress to look at how people who have disabilities live in America, including their limited opportunities to live ordinary lives. Congress saw that the public often thought of people with disabilities as being incapable—or even unworthy—of living in their communities.

People used these wrong ideas as a reason to move people into special facilities. As with other underrepresented groups, people with disabilities were set apart from everyone else and had barriers to living as ordinary citizens. Congress—Democrats and Republicans alike—saw this problem as a civil rights issue, and in 1990, passed a very important law called the Americans with Disabilities Act (the “ADA”).

What does the ADA do?

The ADA says that people who have disabilities experience discrimination that keeps them from living ordinary lives, and that this discrimination is illegal. This law made important changes for people with disabilities to make communities more “accessible”—that is, without the barriers that make it difficult for people with disabilities to get around, to go to the movies, and to do other ordinary things. Some changes brought about by the ADA you see every day are:

- Sidewalks with curbs that have ramps in them to allow people in wheelchairs to cross the street,
- Braille labels on elevator buttons that let people who are blind to move around a building,
- Handicap-friendly restrooms with grab-bars and larger stalls,
- Buses that “kneel” to accept riders in wheelchairs, and
- Parking spaces reserved for people with disabilities.

The Americans with Disabilities Act (ADA) made communities more “accessible” for people with disabilities – removing barriers that make it harder for people to get around and do ordinary things.

These are examples of the “reasonable accommodations” the ADA may require to help people with disabilities to live ordinary lives. The ADA also says public places such as hotels, restaurants, movie theaters and stores must make reasonable accommodations so that customers who have disabilities can also use their services. For example, movie theaters now have special seating areas for people in wheelchairs and special devices for people who have problems hearing.

You probably have seen these and other accommodations, and you probably thought they are a good thing. However, you may not have realized that these changes relate to the civil rights of people with disabilities, particularly their rights to be free of the discrimination that kept them apart from the community.

Other important changes brought about by the ADA are less visible, but equally important. For instance, when employers make decisions about hiring, the

ADA makes it illegal for them to discriminate against you because you have a disability. It also requires employers to make reasonable accommodations that allow employees with disabilities to do their jobs. Some examples are changing a person's work schedule to allow them to go to medical appointments or providing an employee with a visual problem a larger computer screen).

These changes have helped all Americans, with or without disabilities, young and old. Now people with disabilities live at home, are as independent as possible in their daily lives, are part of the mainstream workforce, and have daily interactions with other people, such as family members, neighbors, and co-workers. In doing so, they break down old, damaging stereotypes and let people with disabilities show their true talents and abilities.

The ADA also provides requirements for how state and local governments offer services to people with disabilities. These requirements apply to programs run *by* the government—everything from courts to libraries to voting—as well as other programs, services, or activities that are paid for and administered *through* the government.

For services directly provided by state and local governments, this means that courts have sign-language services available for people who cannot hear clearly, that libraries have large-print books or other formats for people with visual impairments, and that people with disabilities get the assistance they need to register to vote and cast a ballot. Private businesses who offer services provided as part of a government program must follow the ADA, and include doctors and nursing homes paid by the Medicaid program.

Because the states administer Medicaid programs, the ADA protects people getting services through these programs from discrimination. The law requires these programs take reasonable steps to prevent people with disabilities from getting services that segregate them from people who do not have disabilities. In other words, it is illegal under the ADA for Medicaid-funded programs to place people with disabilities into institutions without taking reasonable steps to serve them in the community.

What is Olmstead?

Olmstead v. L.C. (referred to as Olmstead) was a lawsuit about the ADA that went all the way to the U.S. Supreme Court. Lois Curtis and Elaine Wilson, two women with mental disabilities, filed a lawsuit against the State of Georgia, charging they were not getting the services in the community they needed. (Olmstead was the State's mental health commissioner at that time.) As a result, they often had to live in institutions. As people with disabilities, they claimed that under the rules of the ADA, the State's failure to provide community services was illegal. The Supreme Court agreed. In a landmark decision in 1999, it found that unnecessary institutionalization is a form of discrimination. This finding applies to all people with disabilities who are covered by the ADA—young and old—and it does not matter if their challenges are physical, mental, or sensory (for instance, in seeing or hearing).

The Supreme Court's decision did put some limits on what states and local governments must do for people with disabilities who want to live in their own homes. The community services they must offer cannot place an "undue burden" on government programs. What this means is the ADA cannot make a government offer or pay for a community service if that service is far more expensive than services it already offers. Under the ADA, the government also does not have to offer a community service that is so unusual that it would make a fundamental change to the service system. Fortunately, most services people need to live at home are far cheaper than care in an institution, and most are available now, but not necessarily to older people with dementia.

The Olmstead decision has been very important in bringing services for people with disabilities to let them live outside of institutions and as a part of the community.

What does the ADA mean for older adults?

Under the ADA, older adults who have disabilities should be able to be protected in the same way as everyone else, but in many ways, they have been the last to get help from this law. Others may see older adults as “frail” or “sick,” needing the help found in a nursing home. Instead, we can and should see them as people with disabilities. We should make the connection that Alzheimer’s disease and other dementias are not just illnesses; they can disable you, just as blindness or not being able to walk can.

Alzheimer’s disease and other dementias are not just illnesses, they can disable you, just as becoming blind or not being able to walk can.

The ADA provides important protections for people with disabilities, and older adults should fully benefit.

Some important details...

Who is protected by the ADA?

Congress understood that people with one or more of a wide range of health problems faced discrimination and isolation in their communities. For this reason, the ADA covers people with any physical or mental problem that interferes with a major life activity, such as:

- caring for oneself
- performing physical activity
- seeing
- hearing
- eating
- walking
- speaking
- breathing
- learning
- concentrating
- remembering
- thinking

Older adults who have dementia may have problems in one or more of these areas, and for many, these problems are the reasons for feeling they have to move into a nursing home or other specialized setting. The ADA protects them and gives them choices to stay in their own homes.

Where the dollars come from makes a difference under the ADA

Medicaid has special importance to older adults who are at risk of moving into a nursing home or other such facility. Medicaid is a government insurance plan that provides health coverage for people with low incomes. Low-income older adults admitted to nursing homes often qualify for Medicaid; others enter nursing homes paying for it out of their own pockets, but because the cost of care is so high, they spend down most of their savings and then qualify for Medicaid coverage. As a result, Medicaid is the nation's main payment source for nursing home care.

As a government program, however, the ADA requires that states' Medicaid programs take reasonable steps to keep people who have disabilities from having to live in a nursing home because they don't have the services they need to remain in their homes. From a civil rights perspective, unnecessary nursing home admissions mean people with disabilities are separated from their community and kept from living ordinary lives. This is illegal.

Medicaid is the nation's main payment source for nursing home care.

Medicaid programs are different in every state, but in all of the states, Medicaid covers a wide range of services that can make the difference between having to enter a nursing home and staying in your own home. Some Medicaid programs offer special services to individuals to avoid nursing homes. These services include in-home nursing services, help with housekeeping, or even hiring a neighbor to provide help for routine tasks such as shopping. These programs fit with the ADA's requirement that programs like Medicaid take steps to keep people from having to enter segregated facilities unnecessarily.

When these programs and other changes in Medicaid have helped older adults, they have mostly helped those who are frail or who have physical health problems. Older adults who have dementia (such as Alzheimer's disease), but who seem to be physically healthy may not qualify or may be given low priority. People who have dementia—whether or not they are physically frail—often qualify for protection under the ADA. Because of that, the law may be on your side when it comes to Medicaid paying for the services you need to age in place and not need to move into a nursing home.

Does a person need to have Medicaid to be protected under the ADA?

Services paid for through Medicaid are just one part of what the ADA covers. The ADA also applies to all programs, services, or activities operated or administered by states, counties, or cities. Examples of services may include home-delivered meals, legal services, and emergency financial assistance.

Good resources for ADA-covered services are your local Area Agency on Aging or your own county or city health department.

A good resource for finding out what services are offered with state, county, or city funds—and therefore, may be covered by the ADA—is your local Area Agency on Aging or your own county

or city health department. You should think about how these programs can be of help to you and, with the ADA in mind, whether they can better serve older adults with dementia who are at risk of being moved into nursing homes.

It is important to note, though, that these local programs operate on budgets that are much smaller than states' Medicaid spending. Furthermore, these programs generally do not pay for nursing home care. What we have learned from lawsuits using Olmstead to help people with disabilities live in the community, is that if the government spends money on institutional care (such as nursing home care), it can change its systems to move that money to pay for services people need to live at home. Medicaid has been moving towards investing more money into community services, but it still spends billions of dollars on nursing home care each year. Moving some of these funds to support older adults with dementia in their own homes can make a big difference, and the ADA requires those changes.

In summary, the ADA directs local programs (state, county, and city-funded) not to discriminate against people who have disabilities. These programs need to follow the law and to do what they can to allow older people with dementia live outside of institutions. Their small budgets may limit what they are able to do, but they still need to take reasonable steps to help older adults with dementia. Medicaid has a far larger budget; in fact, Medicaid is one of the largest items on a state's budget. The trade-off is that, while city and county programs are smaller, you may have an easier path in bringing about changes through local officials than in dealing with the large Medicaid system.

Is Medicaid the same as Medicare?

It is important to understand the difference between Medicare and Medicaid. Medicare is a health insurance program that covers all adults who are age 65 or older, no matter what their income level. Medicare is federal program, meaning that the federal government funds it and determines what it covers. Generally, Medicare covers far fewer services than Medicaid, especially those services needed by older adults with dementia to stay in their own homes.

Medicaid is a health insurance program for people who have low incomes. Unlike Medicare, Medicaid is a partnership between the federal government and state governments, with both adding to its funding. Unlike Medicare, states have far more flexibility in designing their Medicaid programs to meet the needs of people who have disabilities. Because Medicaid programs include state (and sometimes county) funding, they are a part of the service systems the ADA requires to offer services in the community. Medicare falls under different federal laws, which we do not talk about in this report.

Medicare covers far fewer services than Medicaid, especially those services needed by older people with dementia to stay in their own homes.

What are Home and Community Based Services?

Medicaid has important services called Home and Community Based Services that allows people who have disabilities to remain in their own homes instead of entering an institution such as a nursing home. These services are not usually talked about in terms of older adults' legal rights under the ADA, but it is an example of a program that fits well with the requirements of the ADA. Medicaid can pay for a very broad range of services that can allow people with dementia to remain at home, including:¹

- Alzheimer's/dementia coaching
- Minor home repairs
- Companion services
- Home modifications to prevent injuries
- Grocery shopping
- Systems to prevent wandering
- Home-delivered meals
- Home-delivered medications
- Home health care
- Housekeeping services
- Occupational therapy
- Respite services for caregivers
- Skilled nursing services
- Transportation

The goal of remaining at home is important, as are the services to allow that to happen, but states are not required to offer Home and Community Based Services. Even if states offer these services, they can put limits on who gets them. As you will see, other groups successfully argued that the ADA requires services such as those available through Medicaid's Home and Community Based Services must be offered to people so they are not put in the position of having to enter an institution such as a nursing home.

How has the ADA made it possible for people with disabilities to live in their own homes?

One example of people with disabilities living in their own home are people who have serious mental illness. Serious mental illness, such as schizophrenia or bipolar disorder, is the focus of state mental health systems; these systems often leave out services to older adults who have dementia.ⁱⁱ People with serious mental illness usually qualify for ADA protections because mental illness results in one or more of the physical and mental problems listed earlier in this report (for instance, problems in thinking or concentrating). They have been victims of the kind of discrimination that Congress talked about in passing the ADA. Contrary to popular stereotypes, people with serious mental illness are rarely ever violent and are not “unworthy” or “incapable” of being a part of the community. People who have serious mental illness also have a long history of being kept in institutions, such as state psychiatric hospitals.

With the services they need, people with serious mental illness can live successfully in their own homes as members of their communities. But many people have felt the kind of discrimination and segregation that the ADA prohibits because of how states spent their money, where often people were segregated in psychiatric hospitals for decades.

Knowing that keeping people in institutions is a violation of civil rights under the ADA, the Bazelon Center for Mental Health Law, sometimes in partnership with the U.S. Department of Justice and other legal organizations, brought lawsuits to bring about important reforms. As a result, in several states across the country, thousands of people with serious mental illness who were once living as “mental patients” in institutions are now living in their own apartments and getting the services they need to help them be good neighbors and good tenants. Because of the ADA, states have changed their mental health systems to move their spending from institutions to spending on community services. They also changed their Medicaid systems to pay for the services that people with mental illness need to live as full members of their communities. These services go far beyond therapy and medications; they include a range of supports for the health problems listed above, such as:

- In-home mental health services

- Help with dressing and grooming
- Help with meal preparation and housekeeping
- Transportation to shopping and help in making purchases
- Visits with people who are recovering from their own mental illnesses
- Family and caregiver education
- Help with budgeting
- Rapid emergency help for mental health crises
- Help in getting and keeping a job
- Modifications in people's homes—for instance, ramps for people in wheelchairs—to help people age in place.

Services such as these are letting people who have long-term mental illnesses to get their lives back and to live in a place they call home. Living outside of institutions, they are able to make the kind of choices that most people take for granted; where they live, who they live with, what they eat, when they eat, and so on.

If these services look pretty much the same as those listed as Home and Community Based Services earlier in this guidebook, that should not be a surprise. With some exceptions, no matter what the illness, people with disabilities may need the same types of assistance in order to live in their own homes. Older adults who have dementia generally have led very different lives from people confined in psychiatric institutions. Many have lived in their own homes, held jobs, raised families, and carried out the day-to-day activities of ordinary living. However, like these people with serious mental illness, older adults with dementia also have disabilities that qualify them for protection and supports by the ADA. For them to stay in their own homes, many need the same in-home services that now let people with serious mental illnesses live in their own homes. Just as the ADA has shown itself to be a powerful tool to change services for people with long-term mental illnesses, it can do the same for older adults with dementia.

Olmstead plans

Following the Supreme Court's Olmstead decision, many states created Olmstead plans. These are blueprints for how the state will make changes to their systems under the ADA to make sure people who have disabilities do not end up in facilities and that the state's programs do support people living in their own homes and in their own communities. As we said earlier, the Supreme Court found that putting people with disabilities into institutions is a form of discrimination that is illegal under the ADA. People with mental illness have been kept in hospitals illegally, and lawsuits have pushed states to offer more services to allow them to live in the community instead.

Although individuals who have serious mental illness are an obvious example of people kept apart from the community based on their disability, this separation has a long history in America with regard to people with all sorts of disabilities. Older adults unnecessarily put into nursing homes have been the targets of such discrimination. For this reason, states' Olmstead plans should clearly spell out the steps taken to make sure that older adults get the services they need to remain in their own homes. Olmstead plans should certainly support the needs of physically frail older adults, but they should also address the needs of older adults who have dementia, such as Alzheimer's disease.

Your state's Olmstead plans may be a good place to see how your state addresses discrimination against people who have disabilities.

As we said earlier about people with serious mental illness, the ADA has pushed states to move large amounts of money they were spending on psychiatric institutions to pay for services that let people to live at home. States spend a lot of money on nursing homes. Medicaid pays almost \$50 billion each year for nursing home care nationwideⁱⁱⁱ and, depending upon the state, about half of this spending is state dollars that must meet the standards of the ADA.

There is also a wide recognition that the way states have spent their dollars (through Medicaid and in other programs), results in older adults with disabilities being needlessly placed into nursing homes. For instance, aging advocates in one state found that, "due to limited resources, there is a considerable gap between the

number of older adults currently served and the number that are eligible for... supportive services” that can avoid nursing home placement.^{iv} This happens despite the fact that the services older adults want and need to remain in their own homes tend to be far less expensive than nursing home care. The yearly cost of a private room in a nursing home is now about \$87,600; an assisted-living room costs around \$42,000 a year and a home health aide for long-term care runs about \$45,188 annually.^v

To sum up, your state’s Olmstead plans may be a good place to see how your state addresses needless segregation of people who have disabilities. These plans should specifically talk about the needs of older adults, including older adults who have dementia. They are usually easily available on-line, often through a state’s website. There are several important points to think about in understanding how well your state is doing in complying with the ADA in ways that help older adults:

- First, in its Olmstead decision, the Supreme Court suggested that states may want to create Olmstead plans. It did not require states to do so. Many states brought together representatives of government programs and various disability groups to create Olmstead plans.

Older adults—particularly older adults who have dementia—may or may not have high priority in these plans.^{vi} A lot may have depended upon how loud a voice older adults have in influencing the way state programs are run (more on this later). Two things to remember:

- ◇ States tend to update their Olmstead plans periodically, so even if older adults’ rights to community services were not well addressed, there are opportunities to make changes.
 - ◇ Whether or not a state has a written Olmstead plan, and whether or not that plan includes older adults with dementia, all states still must follow the law. In other words, regardless of what is or is not written in an Olmstead plan, a state still must make sure that its programs do not result in people with disabilities—such as older adults who have dementia—being unnecessarily placed into institutions.
- Another thing to know about Olmstead plans is that there are sometimes big differences between what the plan says and what actually happens. Olmstead plans may discuss older adults who are at risk of nursing home placement,

and state the goal of letting people to age in place. But if states limit people's access to programs such as the Home and Community Based Waiver, many older adults may still suffer the kind of discrimination that the ADA forbids. As one state's Olmstead plan notes, "plans that states cannot implement because of budget constraints create no progress toward achieving Olmstead objectives."^{vii}

In other words, to meet their obligations to older adults who have dementia, states may need to spend money on community programs that support people in their own homes. States are already spending huge amounts of money on nursing home care, including through the Medicaid program. Although Medicaid is complicated and has lots of rules, it gives states "extensive flexibility" to decide who is eligible for Medicaid services and what kind of services Medicaid covers.^{viii} However, that flexibility is limited by the ADA.

In many ways, the 1999 Olmstead decision sent a warning to states that they need to work out problems in the availability of home- and community- based alternatives to nursing homes.^{ix} However, the Supreme Court decided that issue more than 15 years ago—a period during which the nation's older adult population grew larger as the baby boomers aged.^x About Olmstead plans, the question now is whether states are meeting their legal duties to older adults who have dementia, knowing this population is going to grow, in-home services tend to be far cheaper than nursing home care, and the ADA does not allow discrimination against people who have disabilities.

What about special dementia units?

Some assisted living facilities and nursing homes have special units for people with dementia. These units are set up to increase the safety and independence of residents who may have problems with wandering, forgetfulness, confusion and other symptoms of dementia. For some people—particularly those with more advanced forms of dementia—dementia units may be a reasonable option to think about. However, you can install many of the features of these special units in your home, making it safer, reducing the effects of wandering or confusion, and relieving some of the stress on caregivers.

Just as is the case with Medicaid paying for home modifications, such as wheelchair ramps to let people with physical impairments to live at home, people who have dementia also benefit from home modifications.^{xi} Some of these modifications are easy, such as installing buzzers to sound an alarm when an outside door is open, disguising doors that lead to the garage or basement, removing knobs from the stove, and locking up dangerous items. Other modifications, such as making bathrooms disability-friendly, may take more effort.

It is important to remember, that because Medicaid and other public programs offer these services for other disability groups, you can make a strong argument they should support such modifications for older adults with dementia, as well. Likewise, caregiver education and support (including opportunities for time-off or “respite”) can be important to making sure that older adults with dementia do not need to move unnecessarily, including into a dementia care unit. All of these modifications and supports are in line with what the ADA requires public programs to do.

How can you use the ADA to allow older adults with dementia to remain at home?

Although Congress passed the ADA more than 25 years ago, and the Supreme Court issued its Olmstead decision more than 15 years ago, far too many older adults have not seen the benefits to which they are legally entitled.^{xii}

For older adults with dementia, the opportunities to stay at home that the ADA requires happened because of other factors; for example, as a by-product of programs meant for physically frail older adults or programs created to save money because of high nursing home costs. Getting community services in these ways is fine—as far as it goes. Far too often, the types of community services available to older adults with dementia are limited and access to these services is difficult.

For these reasons, it is critically important that families, caregivers, and healthcare providers understand that older adults with dementia have the same legal rights under the ADA as other people with disabilities, including the right to be free from the kind of discrimination that leads to their placement in institutions. Programs that are a part of state, county, or local public systems must make reasonable modifications to make sure older adults with dementia can age in place. One reason these changes required by the ADA have lagged behind other disability groups is that many people affected by dementia (families, social service agencies, healthcare providers, and others) have not fully understood how this important law applies to them. The main goal of this guidebook is to inform—and to mobilize—everyone involved with a person with dementia.

Things that you can do...

This guidebook gives you important information about how services that allow older adults with dementia to remain at home are not only what people want, they are also a civil right. With that information, you now can take some important steps to not only help you or someone you know who has dementia, but to help make changes for others who may become disabled due to illnesses such as Alzheimer's disease

- 1. Educate others.** Far too many older adults, their family members, and professionals who serve them do not know that having a disability related to dementia has important civil rights protections under the Americans with Disabilities Act. Laws and lawsuits are complicated, but the message you can spread is pretty simple:

It is critically important that families, caregivers and healthcare providers understand that older people with dementia have the same legal rights under the ADA as other people with disabilities.

Services that are paid for with public dollars (that is, through state, county, or local government programs) must promote community living for people with disabilities; the Supreme Court says that unnecessary placement in an institution (such as a nursing home) is a form of illegal discrimination.

- 2. Re-think what older adults with dementia need.** Many families feel they have a choice of either continuing to support an older adult who has dementia at home—often with little or no help—or moving that person into a nursing home. The ADA requires that public programs work to offer additional options to allow people to stay in the community. Too often, healthcare providers (such as doctors or social workers) think in terms of what is most readily available, such as nursing home care or a special dementia unit. What you (and they) need to do is begin with the assumption that the person with dementia could remain at home if the needed services were available.

In most cases, these are low-cost services, such as family member education about how to deal with wandering and other problem behaviors, opportunities for a family member to take time-off from the stress of care-giving, help with dressing or bathing, and help in making the home environment less confusing for the person with dementia. Instead of thinking in terms of whether or not to move a person into a nursing home, think through what things you would need to make aging in place work. The lists of services above should be a starting point. What help do we actually need? How often? For how long? Don't worry about getting things exactly right; people's needs change over time, and good services should be flexible. You may not need some types of help for long; other needs may increase. Again, the important thing to remember is that public programs must work to support people who have disabilities to stay in the community.

- 3. Be an advocate for the person and for others with dementia.** If you do not ask for what you actually need, you probably will not get it. One reason that older adults too often have been at the back of the line for community services is that they—and their family members—“go with the flow.” In other words, they accept the choices and recommendations presented to them. As we said earlier, in part this is due to people not understanding what their rights are under the Americans with Disabilities Act. In addition, many families are already at the breaking point when they need to make decisions about nursing home placement. In 2015, 15 million caregivers provided more than 18 billion hours of unpaid care to people with Alzheimer's disease.^{xiii} Most have not been helped by the community supports that the ADA requires; they are stressed out and want a solution to a very difficult and long-term family problem. The key issue, of course, is if programs worked as the ADA says they should, families would not be in this situation, or at least they could delay and better plan for the crisis. Strong advocacy is dramatically changing things for people with disabilities relating to sensory problems (blindness, deafness), physical problems (using a wheelchair or being physically frail), and mental disabilities (such as serious mental illness). Advocacy can have the same impact for older adults with dementia, particularly if family members and other caregivers speak out and raise questions.

4. Look at what public programs are currently doing to support older adults with dementia to age in place. As was discussed earlier, one starting point is your state's Olmstead plan. Does your state have one? Does it specifically include older adults? Does it specifically include dementia? More than 5 million Americans are disabled by Alzheimer's disease;^{xiv} so they not only should not be an afterthought in states' Olmstead plans (if they are included at all), but they should actually be highlighted. Olmstead plans for older adults with dementia also should include more than just the goal of aging in place; they should have specific details about how public programs will let the large and growing number of people with dementia to live outside of institutions and in their own homes. Remember, although Olmstead plans might talk about older adult programs such as Area Agencies on Aging, the state, the county, and local government still have to follow the rules of the ADA and Olmstead. Government programs may include aging services, but that, in itself, does not solve the problem. Does the state Medicaid program heavily invest in nursing home care, but include only a limited Home- and Community- Based Services program? Is there a waiting list for these services, and what is the state doing about that? Are the state, county, and local governments pulling together public programs across departments (for instance, aging, mental health, and Medicaid) so there is a coordinated response that lets older adults with dementia stay in the community? The ADA requires them to do so, but there is a long history of these systems not working together around aging issues.^{xv}

In summary, find out what is—and what isn't—happening in your area. If this information is not readily available, or if it isn't understandable, you may have good reason to think that the rights of older adults with dementia are being not being respected.

Where to go for resources

Once you are ready to look into services for people with dementia, here are some organizations that can help:

The Judge David L. Bazelon Center for Mental Health Law

The Bazelon Center for Mental Health Law advances the rights of people with disabilities through legislative and judicial advocacy. Bazelon Center policy staff pursue mental health reform in federal legislation while legal staff engage with cases to guarantee the rights of persons with disabilities. Although the Bazelon Center does not provide direct services, representatives often act as co-counsel alongside attorneys from other organizations.

Website: <http://www.bazelon.org/>

Phone: 202-467-5730

Protection and Advocacy Agencies

Protection and Advocacy (P&A) agencies provide legal representation to people with disabilities. P&A agencies also offer additional advocacy services, including employment opportunities, educational programming, and accessible housing. P&A agencies are based on location, and each agency is a member of one of two national networks. To find your P&A Agency, look to the national networks to find the P&A agency closest to you.

National Disability Rights Network

Website: <http://www.ndrn.org/en/ndrn-member-agencies.html>

Phone: 202-408-9514

Administration for Community Living

Website: <https://acl.gov/programs/aidd/Programs/PA/Contacts.aspx>

Phone: 202-401-4634

Independent Living Centers

Independent Living Centers (ILCs) support people with disabilities seeking to live independently within their communities. ILCs provide a range of services, from independent living skills training to aid transitioning from nursing homes to community-based residences. ILCs are location-based.

Webpage: <http://www.ilru.org/projects/cil-net/cil-center-and-association-directory#alphaList>

Phone: 713-520-0232

AARP state affiliates

The American Association of Retired Persons (AARP) is a nonprofit, nonpartisan, social welfare organization for people more than 50 years old and fights for older adult issues such as health care, employment and income security, and protection from financial abuse. A list of state offices is available below.

Website: <http://www.aarp.org/states/>

National Association of Areas on Aging

The National Association of Area Agencies on Aging (n4a) is a membership association representing America's national network of 622 Area Agencies on Aging (AAAs). Their members help older adults and people with disabilities live with dignity and choices in their homes and communities for as long as possible.

Website: <http://www.n4a.org/>

Phone: 202-872-0888

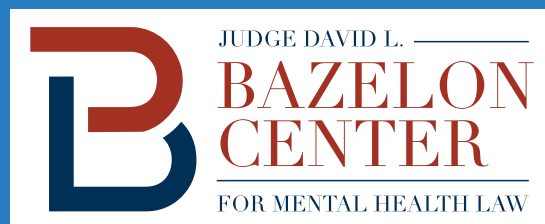
Justice in Aging

Justice in Aging combats senior poverty by providing elderly people with affordable health care, economic security, and legal protection. Justice in Aging provides both direct services for elders and training for elder advocates.

Website: <http://www.justiceinaging.org/>

Phone: 202-289-6976

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- i Kaiser commission issue brief Mass's frail elder waiver
- ii Bazelon Center Last in Line, p. 18
- iii <http://kff.org/medicaid/state-indicator/spending-on-long-term-care/>
- iv New York State Association of Area Agencies on Aging, "Older New Yorkers and the NYS Olmstead Plan" May, 2013
- v Genworth Cost of Care Survey. <http://www.forbes.com/sites/nextavenue/2014/06/19/best-and-worst-states-for-long-term-care/#1a44a59b1bd4>
- vi Bazelon Center Last in Line, p. 4
- vii The Governor's Integrated Services Task Force and Arkansas Department of Human Services, "The Olmstead Plan in Arkansas: A Catalyst for Collaboration and Change" March 31, 2003, p. 5
- viii http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf, p. 29
- ix http://www.longtermscorecard.org/~media/Microsite/Files/2014/Reinhard_LTSS_Scorecard_web_619v2.pdf p. 31
- x <https://www.census.gov/prod/2014pubs/p25-1140.pdf>
- xi <https://www.alzinfo.org/articles/home-modification/>
- xii Bazelon Center Last in Line, p. 1
- xiii <http://www.alz.org/facts/>
- xiv <http://www.alz.org/facts/>
- xv Bazelon Center Last in Line, p. 8



1101 Fifteenth Street NW, Suite 1212
Washington, DC 20005-5002
www.bazelon.org